

22 October 2019

We are NDIS Appeals Advocates. AMIDA is a not for profit organisation operating across Victoria, based in Melbourne's CBD. As NDIS Appeals advocates, we assist NDIA participants with appeals, or assist potential participants with NDIA access issues.

We are concerned by many aspects of the NDIS which fall short of the ideals of the scheme as it was envisioned at the time of proclamation of the *NDIS Act 2013* (Cth). We have some comments in response to the DSS Discussion Paper, *Improving the NDIS Experience: Establishing a Participant Service Guarantee and Removing legislative Red Tape* (2019).

Our concerns originate from individual instances where the participant has met unfairness, obfuscation or delay. Our concerns also include systemic problems we have encountered as advocates when dealing with the NDIA. We can provide numerous examples of each, but will limit the examples in this paper. We are happy to speak with you in more detail if you would like.

Our comments are in 3 parts. The first part relates to principles of the NDIS which should be in a Participant Service Guarantee. The second part relates to the participant pathway, particularly on access and appeals. The third part relates to the legislative framework. We use the acronym PWD to refer to a Person With Disability. Our paper concludes with a list of our recommendations.

## **A. Our comments concerning the Participant Service Guarantee**

The Discussion paper identifies seven principles for a Participant Service Guarantee. We agree that each of those 7 principles should be included. We have identified a further 5 principles which are equally important and should be included as principles of the NDIA service standards. They are consistency, transparency, integrity, responsive and accessibility.

- a. Consistency.** It is a principle that is relevant in many aspects of the NDIA. It is appropriately balanced with the principle of individualised needs of PWD. If individualisation is not tempered by consistency, randomness dominates predictability; it can even become capricious decision-making over fairness.

This is an example: We have a PWD client who is a 2 year old child with microcephaly, cerebral palsy. This child is PEG-fed and who cannot weight bear. His plan is \$19,000. This is not comparable in any sense to other children with similar functional impact.

Another example: We have 2 separate clients with remarkably similar disabilities, yet markedly different plans. Both are primary school-aged children with the same

diagnosis of severe childhood apraxia of speech, severe language disorder and mild intellectual disability. They both see the same paediatrician, same specialist, and both participate in the same research project at the Murdoch Children's Research Institute. They both live with their married parents and their two siblings. They are 3 months apart in age. One lives north of Melbourne's CBD, the other south. One has about \$17,000 in their plan, the other \$40,000.

- b. Transparency.** This should be a stand-alone principle of the NDIA service standards, not buried within a principle of "merit". It has application beyond issues of merit. It also has application beyond decision-making. Transparency also requires clarity in communication; not obfuscation or confusion. There should be transparency in all forms of communication, operational guidelines, data collection, policy application and complaint resolution.

This is an example: The website should say what it requires as well as what is not required. The fact that the NDIA have removed from their website some suggested terms for Service Agreements to avoid confusion of the non-requirement for Service Agreements to be in writing, does not clarify. The website should state that Service Agreements do not need to be in writing in a deed form for the NDIA. It could then state what may be recognised as evidence of a Service Agreement, eg, notes of a conversation, a recording etc.

- c. Integrity.** Statements by individual NDIA representatives should always be true and accurate. They should be respectful. They should not be hypocritical or demeaning or unduly intrusive.

This is an example: At a recent AAT conference, the NDIA was represented by an internal lawyer, and, an external lawyer who is a partner of a law firm. The participant was represented by one advocate. The advocate queried the need for the extensive and intrusive set of questions for a participant with a psychosocial disability. The NDIA lawyer repeatedly justified the questions on the basis of concern for spending of public money on a participant; that the NDIA had to be careful how our taxpayers money was spent. The irony, let alone the hypocrisy, of the cost of 2 senior lawyers paid on the public purse against a participant without legal representation was lost on the NDIA lawyer making the comments.

Another example: The NDIA should not remove the rights of a PWD in exchange for an early plan review. Many PWD are offered an early planning review meeting in exchange for withdrawing an Internal Review, which removes the right to appeal to the AAT.

- d. Responsive.** The NDIA should be appropriately responsive to PWD.

This is an example: 11 months after lodging a Request for a Review of a Reviewable Decision, the NDIA made a call to the participant to inform them that the NDIA had received the RORD. The purpose was not even to say the RORD had commenced. The response was inappropriately delayed and provided no information or reason.

Another example: The NDIA should not create blocks to advocacy by insisting on advocates supplying middle names, dates of birth and other personal information. The NDIA has no record against which to verify this information.

- e. **Accessibility.** Representatives of the NDIA must be contactable by the public for consistent service. Privacy of staff must be balanced with the operational needs of a government service. NDIA representatives should provide an ID reference (if not surname) on all communications. NDIA should provide a means for PWD or advocates to return contact with an NDIA representative, either by phone or email.

This is an example: Many NDIA representatives will not leave their name or number on a message so the caller is unidentifiable. Most NDIA representatives will not provide a direct contact detail of a phone number or email address. The NDIA secure email system works against advocates managing caseloads; the secure emails do not permanently remain on the secure system and therefore must be copied over to another system for record keeping of advocates. But email trails are difficult as the systems are incompatible, by design.

We also support the inclusion of the seven principles identified in the Discussion Paper. We leave it to others to supply examples of the seven, although with time, we could supply plenty.

We assume the Guarantee is a legislative inclusion into the *NDIS Act 2013* (Cth). We are concerned that the inclusion of a Guarantee of these principles will not alone change the NDIA attitude and culture. Enforcement mechanisms of the principles should be considered, including increased funding and investigative powers of the Commonwealth Ombudsman over failure of the NDIA to implement its Guarantee.

It is our view that none of the 12 principles are acknowledged in practice, or adhered to, by the NDIA. The NDIA must adhere to these principles to ensure it meets its current statutory objectives, let alone the proposed Guarantee. But to do so, it will have to re-evaluate its whole approach to dealing with the public. It will need to acknowledge it currently has serious failings in every one of these 12 principles.

The NDIA will need a cultural shift if these principles are to mean anything. The NDIS created the expectation that it would not operate like previous government systems. The NDIS was established as an individualised support system for PWD. It promotes itself as the new way to provide support for PWD (*About the NDIS*, video, [www.ndis.gov.au/understanding/what-ndis](http://www.ndis.gov.au/understanding/what-ndis)). Yet it has lost sight of these aims of connecting with PWD. It is operating like other government agencies, mired in self-serving bureaucracy, more concerned to protect its own, than serve others. The 12 principles of service standards are really an attempt to bring the NDIA into line with the NDIS ideals.

As to evaluating service standards, the timing and wording of the question is an important consideration. As an example, consider the NDIA' exceedingly high satisfaction rates. These surprise many. But results are skewed when they are asked after a positive experience and

not after negative experiences. One of our clients was asked by the planner at the end of a planning meeting if the NDIS was improving his life and if he was happy with the NDIA. The planning meeting had been very positive, and the participant replied “yes”. The resulting plan did not reflect some significant issues discussed, or the confidence of the planner. Despite attempts to resolve the issues, an Internal Review was submitted with a week or two of receiving the new plan. The participant is now not happy with the NDIA and the NDIS has made his life worse. But he has not been asked the satisfaction questions since the planning meeting and his current views are not reflected in the NDIA satisfaction rates.

## **B. Our comments concerning the participant pathways, access and appeals**

- a. The Access Request Form (ARF) causes many issues.
  - i. The ARF does not clearly specify the type and extent of material required to describe the significant functional impact of each domain. Many access requests are denied because the GP has not provided the type of information required. GPs do not know the process or the language of the *NDIS Act*.
  - ii. GPs and medical specialists know the language of medicine. They consider that the diagnosis they give is sufficient to determine the limitations of a PWD and therefore NDIS access. Yet they are filling out ARFs that are meant to describe functional impact of disability and not have a medical focus. The process is logically flawed and explains many denials of NDIS access.
  - iii. Significant functional impact of domains is an area of expertise of OTs. It would be more appropriate that they complete an ARF than GPs. But not all PWD have an OT prior to NDIS access, and many could not afford one. At least OTs should be able to complete an ARF.
  - iv. Insufficient resources and finances have been provided to include GPs in the cultural change so they understand their role in NDIS access. As the entry point, their role is crucial. Therefore it is imperative they all understand their role. There is an enormous demand for education of GPs and specialists in what is required in their reports. It is different to a medical report to another medical specialist.
  - v. Importantly, the ARF should be accepted when completed by anyone, provided medical evidence supports the statements.
  - vi. A GP should be able to issue a type of Medicare “NDIS Access Support care plan”, along the lines of a mental health care plan. This model could be explored and expanded to allow PWD to access allied health professionals to inform and complete the ARF under Medicare.
- b. The NDIA has an expectation of evidence that participants often cannot deliver, even if deserving.
  - i. Participants are beholden to the medical specialists reports. The specialists often struggle to write reports or letters in the terminology required by the NDIA.
  - ii. Specialists are critical that they do not get paid for the report writing for the NDIS; many participants cannot afford it. The specialists are expected to increasingly carry this burden of report writing for free or the cost of a medicare-funded consult.

- iii. Specialists can react negatively to a request for a medical report for the NDIS. Some medical specialists resent the bureaucracy of the NDIA and the imposition on their medical time.
  - iv. As a consequence, the reports are frequently not of a sufficient quality.
  - v. The NDIA takes a heavy-handed legal response to a system designed to minimise lawyers so individuals are empowered.
    - The idea was for PWD to take their case on merit to the AAT for review without needing lawyers. The NDIA do not take that approach at the AAT, often with QCs or law firm partners representing the NDIA. Even at AAT case conferences, the NDIA will often have 2 lawyers, as opposed to a PWD and their advocate.
    - The NDIA will contact clients with appeals before the AAT without speaking to the advocate first. When a PWD has a cognitive impairment, this can, in reality or in appearance, trick the PWD into discussing matters that they would otherwise be advised not to. The PWD with cognitive or psychosocial issues may not understand the implications of the law and nuance of the issues before the AAT. At worst this is unethical behaviour if the NDIA relies upon or underhandedly utilises the information gained from a confused PWD in this manner.
  - vi. The NDIA asks for clarification of issues when participants go to the AAT. These can be detailed and intrusive questions for a person with mental health issues, and even when that is pointed out to the NDIA lawyers, they insist the questions be asked. The NDIA is overly legalising the process at the AAT level. It has the appearance of scaring off participants when they are usually alone, with at best an advocate, and they face a lawyered up NDIA, with QCs and law firm partners.
- c. Greater recognition and cooperation with advocates.
- i. Advocates make issues clearer for planners and delegates; the NDIA should communicate with advocates more freely and openly. As an example, the NDIA should email ARFs to advocates if requested; and email new plans to advocates whenever they are listed as a contact.
  - ii. Although agreement has been made with the CEO (April 2019) that advocates can use their own organisations' Consent forms, some NDIA representatives are still asserting (Sept 2019) they cannot accept anything but an NDIA Consent form. To clarify this each time is such a waste of everyone's time. This is apparently because the NDIA's protocols and policies are not clearly explained to all its staff, however employed. The NDIA must ensure advocates are respected and trusted at all stages of the process.
  - iii. If a participant has an advocate, the advocate should be contacted each time there is a need for communication. Sometimes the NDIA ignores the advocate and makes arrangements or requests evidence without the advocate knowing. Many PWD do not know their appeal rights to the AAT are removed by this arrangement. And it is not the place of the NDIA to explain a participant's rights when they are attempting to remove them.
  - iv. Respect for advocates includes the NDIA making more than one attempt to contact an advocate if they do not answer the first phone call. Especially when

the NDIA will not leave a message or contact number or email, it is poor recognition of the role of advocates to only make one call attempt. Advocates are extremely busy and under pressure. And most work part time.

- d. There should be greater continuity of planner involvement with each PWD.
  - i. The scheme has been promoted as responsive and individualised. The separation of contact between PWD from the actual decision-maker voids the system of empathy. The NDIA partner or planner who meets the PWD has a much greater understanding of the issues than the plan decision-maker.
  - ii. The planner should be able to build relationships of communication and trust with the PWD.
  - iii. The planner should be able to make planning decisions. That is how the system has been promoted and the expectation in the community. If that is not how the system operates, then the NDIA should be transparent in that process.
  
- e. Capacity for light touch reviews to fix minor errors.
  - i. Light touch reviews for minor errors should be available. Currently, the preparedness of the NDIA to do a light touch review is so varied as to be random. It should not depend on particular delegates, or a limited (1 week) time period, or only before a review has been requested. These are excuses we have been given.
  
- f. Communication needs to be clearer.
  - i. Simple statements are necessary, in letters and on the phone to participants. Short sentences such as “we have received your documents requesting a review”, “we have 2 weeks to decide whether we will review your plan”, “we will start your review within 14 days”, “we will start your review now” or “we will decide the review as soon as reasonably practicable”.
  - ii. Dating and posting of letters should be timely. Participants are confused by letters arriving in the mail with a letter dated weeks or months earlier; with envelop dates without a sensible time connection to the letter’s date. This is surprisingly common.
  - iii. Some delegates are so sparse in their communication as to be misleading. Some are so brief as to not explain the decision. As an example, the delegate should be able to explain the SDA amount and how it is calculated on type, category and location. Some delegates do not provide reasons to an Internal Review because they think that a statement that each criterion is either met or not met is a reason.
  - iv. NDIA material on the website is not easy to download as it is uploaded across multiple pages. The Rules and Operational Guidelines are examples. The OG should be accessible as a single pdf to facilitate the making of hard copies of the whole of the document.
  
- g. The issue of informed consent by those with an intellectual disability are numerous and complex. Those with significant reduction in cognitive capacity and non-verbal are particularly susceptible.

- i. Many do not have family, guardians, trustees or even NDIA nominees. OPA does not want to be involved in many of these cases if their life is relative stable. State Trustees are not involved in non-financial decisions.
  - ii. Good Support Coordinators and the involvement of an advocate can help these people. But without those supports they are vulnerable. With those supports, the NDIA raises issues of consent.
  - iii. These people can be removed from the NDIS and transferred into aged care by others with another motive. Motives maybe freeing up hospital beds or releasing a Community or DHHS housing place. This is being done by hospital staff or a house staffer, without guardianship and without exploring additional supports from the NDIA. Given the delays and lack of response to crises by the NDIA, hospitals and SDA operators are routinely shifting PWD to aged care.
- h. All Internal review outcomes must be in writing and include reasons. Reasons must be sufficient in law.
  - i. It is not sufficient as a reason to state a PWD does not meet the criteria. That is not a reason. It is a decision.
  - ii. Reasons must be detailed with findings based on material facts referring to evidence and not simply a statement that legislative criteria are met.
  - iii. We have numerous examples of Reasons statements on a Review of a Reviewable Decision simply stating “the participant met/did not meet the Criteria of section x”. This does not facilitate resolution or AAT review applications.
- i. Participants should not be offered an early plan review in exchange for the participant waiving their internal review.
  - i. PWD should certainly not be pressurised to waive their internal review. Pressure frequently happens with the NDIA saying “your review will go to the bottom of the pile”, which is distressing to someone who has already waited many months.
  - ii. Most people do not understand their rights, and are often told by the NDIA to decide immediately, which prevents them asking their advocate (if they even have one).
  - iii. The NDIA should advise PWD that their rights may be affected. The NDIA should not give the advice on rights, but advise the PWD to seek independent advice from an advocate or lawyer.
- j. The quality of LACs and NDIA staff varies enormously
  - i. A PWD employed by the NDIA does not mean that person understands all problems faced by another PWD in a planning meeting. Communication issues differ with disabilities and people.
  - ii. People who are Culturally and Linguistically Diverse (CALD) have different issues. Sensitivities to CALD people are not automatic because the planner is themselves a PWD.
    - One example we had was with a planner with a hearing disability. The mother was clearly submissive because of her culture; she was softly spoken and hesitant in her responses. The male planner repeatedly took her first “mmm yes” as agreeing with his statements, when in fact she was not.

Interjections by the advocate on each question enabled the mother to explain each answer more, showing that she did not agree with the planner's statements. The planner should have been far more aware of the way in which she was replying. The planner would have got the completely wrong understanding of the extent of the child's disability, except in this case an advocate was present.

- iii. NDIA planners and LACs should not shame parents of children with a disability.
  - On numerous occasions in planning meetings have advocates heard the NDIA telling parents that supporting their child with a disability is the role of parenting. Advocates have witnessed parents backing down from asking for needed supports, eg, personal care for an incontinent 13 year old girl.

### **C. Our comments concerning the legislative framework**

- a. There is no need for a time frame under s26(2)(b).
  - i. It is burdensome on potential participants and a cause of stress. Obtaining medical reports takes time, especially for specialists. There are often lengthy waiting periods for appointments, and specialists can take weeks to provide the report. The incentive to speed up the provision of reports is on the PWD to obtain access and funded support. And the waiting periods for specialists are largely out of their control.
  - ii. There is no burden on the NDIA if the potential participant takes months to return with evidence. There is no financial cost as funds are not being provided. There is no value to the NDIA in having a time period specified. The reference number for that PWD will remain in the system whether they return or not.
- b. Rename reviews for clarity and in accordance with administrative law.
  - i. Plan Reviews and Unscheduled Plan Reviews under s48 should not be called 'reviews' to distinguish them from a true review. They should be called Plan Updates or Plan Reconsiderations or Plan Revisions. The same planner can make the decision as the previous decision for that participant.
  - ii. Section 100 reviews should be called Internal Reviews. It is 'internal' because is reviewed within the NDIA. It is a 'review' in administrative law because the original decision maker does not make this decision. This also distinguishes them from external AAT review. The term 'Review of Reviewable Decision' is cumbersome and difficult to say; it is baffling in meaning to those not familiar with administrative law.
- c. Provide a legislative time frame for the completion of an Internal Review
  - i. The only time constraint on the NDIA to complete an Internal Review is that it be completed 'as soon as reasonably practicable' (s100(6)). The NDIA Internal Review system is notorious for Internal Reviews commencing 6, 9 or 12 months after the request was initially submitted. The completion date is frequently 12 months after the review was lodged. We have many examples. One is that an Internal Review was commenced 4 months after lodging (with the reviewer contacting the mother of the PWD and the advocate) and then took a further 8 months to complete. This is the norm, not the exception in our experience.



- ii. On any version of 'reasonable', the delays currently being experienced are contrary to the time frame of reasonableness. The completion of an Internal Review should be commensurate with the operative length of the initial decision. Most plans are for 12 months; an Internal Review should be completed within a quarter of the time of the length of the plan, ie, within 3 months from when it was submitted.
  - iii. The Act should clarify the time frame for completion of an Internal Review. The method most in keeping with the 12 principles identified in this response is to specify that a s100(6) review be completed with 3 months of the request.
  - iv. Currently the Act is unclear whether commencing the Internal Review within a reasonable time is sufficient adherence for the NDIA to avoid AAT jurisdiction, even if the NDIA then take 10 or 12 months to complete the review.
  - v. The Act (or the *AAT Act 1975 (Cth)* ) should clarify that the AAT's jurisdiction is triggered if the Internal Review is not completed within a reasonable time.
  - vi. Some decisions of the AAT claim s100(6) raises a jurisdictional issue and that an external review cannot be based on the lack of a reasonable time under that section. This is not the place to argue against that, but we refute that legal argument. But it is imperative that the AAT jurisdiction trigger and the corresponding time frames are clear. With no clear trigger for AAT jurisdiction, the effect is a denial of a person's natural justice and access to their legal rights of appeal. The AAT should not condone the NDIA delays on a spurious legal argument of jurisdiction that fails to recognise and evaluate the participants' legal rights of appeal.
- d. Provide a legislative basis for medical and allied health specialists to obtain a minimum fee for report writing.
- i. This could be a Medicare line item or covered specifically under the NDIS.
  - ii. There should be provision for GPS to complete ARFs and for other reports required for access. Many people are not accessing the NDIA because they cannot afford the fees for a report for evidence to obtain access. Examples from our experience include separated parents with children with ASD and people with an intellectual disability on the DSP
  - iii. At present the only reports funded under the NDIS are for assessments once a PWD has a plan, and then they are only funded with a view to increasing or decreasing the supports in the following plan.
- e. The Operational Guidelines (OG) with respect to Transport are inconsistent with law and *McGarrigle*. This lacks integrity.
- i. The OG on transport have removed the statement that transport funding is considered a contribution. But the 3 levels remain and are structured in criteria and amount as previous. The 3 levels are still a contribution but just not called that. The 3 levels are still contrary to the law that requires a support be fully funded where the support is reasonable and necessary.

## D. Recommendations

1. There should be 12 principles in the Participant Service Guarantee. We support the inclusion of the 7 named in the Discussion Paper. We add a further 5: consistency, transparency, integrity, responsive and accessibility;
2. The ARF should be accepted whoever completes it;
3. Provide education of NDIS cultural change for GPs and specialists, together with an expectation of report writing;
4. Email material to advocates on request, such as ARFs, past plans, letters of denial of access, decisions;
5. Automatically email new plans to advocates for any client they are assisting;
6. Ensure all NDIA representatives know advocates can use their organisation's own consent form;
7. If a PWD has an advocate, the NDIA should contact the advocate first;
8. The NDIA should make repeated attempts to contact an advocate, not just one;
9. The planner should make the plan decision;
10. Formalise the light touch review process;
11. Reasons for all Internal Reviews should be according to law;
12. Clarify consent for PWD with significant cognitive impairment;
13. Urgent increased funding available for PWD who have sudden increases in need. Hospitals and SDA and SIL providers must be required to facilitate notification of crises to the NDIA to avoid inappropriate placement of PWD into aged care;
14. Do not remove the rights of a PWD; do not make deals to do early plan reviews;
15. Employ 5 times more NDIA staff;
16. Train all staff properly across all areas;
17. Remove time limit for access under s 26(2)(b);
18. Rename the review stages as Plan Updates (s48), Internal Reviews (s100) and External Reviews (AAT);
19. Specify a time limit of 3 months for completion of s100(6) Internal Reviews;
20. Develop an "NDIS Access Support care plan" to facilitate evidence gathering for ARF;
21. Fund medical reports for NDIA access requests as a Medicare item;
22. Fund medical and allied health reports for NDIA Internal Reviews and External Reviews as either a Medicare item or NDIA item;
23. Remove the 3 levels of funding under Transport OG;

## **Conclusion**

You may consider some of these issues to be outside the Terms of Reference. These issues all occur due to bureaucratic red tape and insufficient legislative guidance and all need to be resolved.

If you take a narrow view of the inclusion of some of these issues, you should recommend the residual issues be addressed by other means. One suggestion is to refer them off to the Joint Standing Committee on the NDIS.